

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Bendigo — 17 October 2016

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Ms Shantelle Grant, Macedon Ranges Autism Network.

The CHAIR — Thank you, Shantelle, from Macedon Ranges Autism Network. I know it was short notice, so we really do appreciate you coming along today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

We are really running behind time. We have a site visit to follow out at Kangaroo Flat SDS, so we would appreciate it if you could give a very brief run-down of what your group does. As follow-up, if we do not have enough time to get through what we want to talk about today, if you would not mind perhaps providing information to our secretariat post the public hearing, that would be much appreciated.

Ms GRANT — Not a problem.

The CHAIR — Over to you, thank you.

Ms GRANT — First, I would like to thank the committee for their invitation to attend today. My name is Shantelle Grant, and I am speaking on behalf of the Macedon Ranges Autism Network — I may refer to them as MRAN throughout the speech. I have been involved in the group since its inception in 2011. I have an 11-year-old daughter who has a diagnosis of autism spectrum disorder and a comorbid diagnosis of anxiety disorder. I am the leader of two PlayConnect playgroups in Romsey and Sunbury run by Playgroup Victoria. PlayConnect programs are federally funded. The future of these, unfortunately, is unsure as this will change with the implementation of the NDIS. Playgroup Victoria are well positioned in the field of autism and play, and as well as working with parents, it is Playgroup Victoria's plan to work with all playgroups to make them autism friendly in the future. The group is a safe environment for parents to share experiences while learning some strategies to help their children develop.

I am also the convener of the annual Light it up Blue autism awareness campaign in the Macedon Ranges, and they have run since 2012. The MRAN is a not-for-profit network that has operated for nearly five years in the Macedon Ranges. We have a membership of over 350 members in town such as Woodend, Kyneton, Romsey, Riddells Creek, Gisborne, Sunbury, Kilmore and Wallan. On average we have two to three new members asking to join a group each week. We do believe the Amaze statistic of 1 in 88 to be fairly accurate in relation to our region. The group's membership involves families and individuals that represent the full demographic of our region.

The group reflects our local communities and represents families with children and youths of all ages, as well as adults with a diagnosis of autism spectrum disorder. The MRAN currently runs a closed Facebook support group, fortnightly coffee mornings, the Light it up Blue advocacy and awareness campaign, a community of practice in which local professionals have an interest in our ASD community, a youth engagement program, our weekly youth group that runs with the support of the Macedon Ranges shire, post-diagnostic workshops for parents with recently diagnosed children and Parents Helping Parents, a peer mentoring program.

There is also the Secret Agent Society, otherwise known as SAS, which you may have heard of. We subsidise the running of this evidence-based social skills program for children between 8 and 12 years. There are also the following: a girls' social skills group, run in conjunction with Macedon Ranges Health, for girls aged between 6 and 8 and 9 and 12 years; the Lab, which is about to start in Kyneton in partnership with Windara disabilities services; the Brick Club, which is a volunteer Lego group for school-age children; research partnerships; and other partnerships with local community organisations.

MRAN aims to provide opportunities for those with a diagnosis of autism and their families to participate in their community to the extent that they desire and be supported whilst doing so. Macedon Ranges is fortunate to have many skilled and experienced practitioners working with families and individuals. Unfortunately waiting for these services is long, and some services have closed their books. Private services for psychiatry and paediatricians are all but impossible to access unless families are prepared to travel to Melbourne or Bendigo. Local government services are supportive of our group, offering grants for projects such as the youth group, fundraising barbecues and event venues.

It is evident from many discussions within the group that the school system for students with a diagnosis of ASD in Macedon Ranges is not adequate in meeting the needs of students and their families. Lack of appropriate schooling options for children with ASD can have severe financial, emotional and social impacts on families, leading to isolation from local communities and services.

Some of our significant issues are: one, inconsistency in criteria for funding students; two, inappropriate criteria for additional assistance for students with ASD in Victorian government schools — you know the statistics on that, I do not need to go through that again; three, schools refusing full-time enrolment, forcing parents to accept only part-time enrolment; students with borderline intellectual disabilities not eligible for funding or able to access special schools. In the Macedon Ranges there is no access to autism-specific schooling and access to specialist schools means extensive travel — up to 90 minutes to and from schools outside the shire for children who struggle to manage a typical school day let alone the additional hours on top of this with travel. Student and family support reduces significantly when they enter the school system and further reduces as the child progresses through school.

The seventh point, inconsistent staff proficiencies regarding the knowledge of ASD and behaviour support; eight, duplication of resources leads to inconsistent training of staff, both within schools and between schools; nine, a lack of social skills training for all students leading to bullying incidents further isolating students; ten, the extent of the financial and emotional strain on families who are required to continually advocate for their children. This means many of our parents are unable to hold down a full-time job due to the increased demands of appointments, therapies and school callings.

Students with ASD have many abilities that can be strengthened and encouraged in a school setting. They have the ability to contribute positively to the school environment and make a difference within their communities. We are hoping the education department in Victoria will work towards providing consistent and adequate supports to allow our children and youths to access the schooling system. With these concerns in mind we have proposed the addition of a specialist centre of excellence within the Kyneton education precinct to offer schooling choices for families in our region. I would be delighted to leave our prospectus with the committee for your consideration.

There are many issues facing our families and individuals in our region. We hope that the introduction of the NDIS will enable families to access services more readily within our local communities. We also hope that these services are adequately trained and offer evidence-based outcomes and supports. Our greatest concern with the NDIS is that there will not be enough service providers in our region to meet the anticipated needs. MRAN has a vision that all levels of government will seek out the advice of community groups such as ours as well as suitably experienced professionals to ensure that they are providing services and supports that will make the best difference to the lives of individuals, families and carers with autism.

Thank you again for this opportunity. Our members have indicated they would be happy to meet with you individually at any time. Just on a personal note, I would really like to thank you again for the invitation to attend today. Fiona Le Nepveu, who is the founder of the Macedon Ranges Autism Network was unable to attend but sends her best wishes and would like to talk to you further if required.

The CHAIR — Thanks very much, Shantelle. Was your network aware of the inquiry before you were contacted?

Ms GRANT — Yes, we were.

The CHAIR — Good. I am just curious about how far and wide across the autism sector the inquiry is known.

Ms GRANT — Yes. We speak regularly with Mary Anne Thomas — —

The CHAIR — The member for Macedon.

Ms GRANT — She represents Gisborne in the Macedon Ranges, so we were well aware of inquiry.

The CHAIR — I have been struggling to come to terms with a couple of things that have come up through today's session. One of them is that I am finding it really hard to comprehend how certain groups and individuals feel that they have the capacity to speak on behalf of those with autism when the spectrum is so big

and so wide and so diverse, particularly for those on the spectrum who might have an intellectual disability or other form of disability as well. I am just wondering: what is your view around advocacy? Not all autistics are the same, as we know. I am struggling with this view that we do not use terminology that describes high functioning and low functioning anymore and the challenges around all of that, but in my mind I am still seeing, for want of better terminology, high-functioning autistics speaking for those who are low-functioning autistics, and I do not have a better way of describing it than that. I just want to know what your views are around all of that.

Ms GRANT — Within the Macedon Ranges Autism Network, as you can imagine with 350 families either contacting us directly either through email, phone calls, attending our coffee mornings, our closed Facebook page has been quite an asset to families, especially late at night when they are going through some really hard yards, and quite often it is the only time you get to vent and, being quite anonymous, I guess it is a lot easier for them to say what the issues are.

With the Macedon Ranges Autism Network we are supporting parents on their journey with autism. Quite often some of them will be going through a new diagnosis, and we still have adults that are getting diagnosed as well. With the movement that is happening at the moment, with the change in language that is being used and with the issue of autistic adults speaking for children that are non-verbal or that have intellectual disorders it is very difficult. Personally I fear that it is going to create a division within our autism world. This is what I come across when I am working with PlayConnect groups. Our families are from nought to six, and they are at that raw stage when they are presenting with a child and they do not know what is wrong with it. They are going through the diagnostic criteria and there are waiting lists. Some of these children do not speak. Some of these children will never speak. Some of these children will not walk. They will never cuddle their parents. They will never tell their parents that they love them. Yet every day these parents get out of bed, get their kids dressed and bring them to these groups.

For an autistic adult to speak for that child, when they do not know that child, they do not sleep with that child — or maybe not sleep, like in my case; it has been 10 years since I had a full night's sleep — I find it difficult. I find that parents know their children the best. They wake up, they sleep, they feed and they live with these children every day. These children depend on them to feed them, depend on them to dress them, depend on them to advocate for them in every way of life, whether it be social skills, self-managing, feeding, dressing or toileting. So I struggle with an autistic person advocating for that child when they do not know that child, especially when you say no two autistic people are the same. We cannot sit there and say, 'I know everything about you', because I am sorry but you do not.

As Macedon Ranges Autism Network we support all individuals with autism. I know there is a voice for autistic adults that should be heard, but I also think there is a place for carers and parents and professionals. I think we really need to be clear on that. This is a personal opinion. As the Macedon Ranges Autism Network we need to listen to all people and all of our community members, but as a parent who is very driven — I am very passionate and I will keep talking, so give me the wave — I do believe that we need to be really aware of this so that it does not create a division within our autism community. Within schooling, within the community, within legislation and within everything, we need to listen to parents as well. I just do not think we can cut them off, because they are the experts on their children.

My fear with the change in language, and I have said this before, is that I understand the need of autistic adults wanting to be heard and not wanting to be called this, that and the other. Autism spectrum disorder is a disorder. It is a neurological disorder of the brain. That is the diagnosis. If we start changing language and changing things to diversity, when we look at supporting our families and supporting our children, if we take off those words, how are we going to get support from governments when we say, 'It's not really a disorder; it's not really a disability'? My fear as a parent, and this is the parent talking with you right at this point, is that if we change these languages and change these things, how can we expect governments to support us? I hope that answered your question.

The CHAIR — Yes, thank you. I think it clearly identifies as well the need for advocacy, particularly for parents who might not be able to advocate for their children. There is a space for that, but at the same time the voices of parents of children on the spectrum clearly need to be heard.

Ms GRANT — Yes, and part of my journey is educating parents and supporting parents, which is what we try to do through MRAN and even through Playgroup Victoria. We try to give parents those tools to educate

themselves, because if there are mental health issues within parents, marriages suffer. My marriage unfortunately suffered, not 100 cent because of the diagnosis, but it does make home life a little bit harder. It is about the education of parents and the supporting of parents through that journey and giving them the tools and the access to the things that they need to process and move through that journey of autism.

Ms McLEISH — Thank you, Shantelle. I am not sure of your background or what brought you to this, but you have been extremely articulate, and I am sure that as everybody is looking at your Facebook page they are probably looking at Doctor Google as well and looking for all sorts of information. Can you tell me, where do you think research is lacking?

Ms GRANT — I was impressed at the Amaze conference this year, sitting and talking with the CRC — I do not know if you are aware of that — —

Ms McLEISH — A couple of us did go to the Amaze — —

Ms GRANT — Autism CRC — are they presenting? I was really impressed by the projects they are running at the moment. They are looking at the biomedics. They are doing research into the cause of autism, and they have three projects running at the moment: biogenics, looking at the cause of autism; the second one is schooling and the third one is looking at GPs and at how they can structure that. That is all research based.

Ms McLEISH — Who is conducting that?

Ms GRANT — The Autism CRC — Professor Whitehouse. He has presented to you in this forum before. That impressed me. I felt that was really good. There have been a lot of research projects that have been done in transitioning children in school. There have been transition programs done by Dr Avril Brereton, for example, transitioning children from kinder to primary school. That has also just been extended from primary school to high school. They have just done an online version. Things like that are really moving forward, and it is the research like that that is making a difference.

Ms McLEISH — Thanks. We are only allowed one question.

Ms COUZENS — I am trying to pick my question now. What impact do you think your group has had on families?

Ms GRANT — I say it with a smile: fantastic. I have parents that have come up to me, especially when we have had family barbecues. We like to invite the families along and the kids along. We make them autism-friendly. One family came up and said, 'If it were not for you and your group, I would never have taken my children out in public or to the supermarket'. To me that speaks volumes. It makes me cry. She had twin boys on the spectrum. She said, 'If it were not for the support of your group, Macedon Ranges Autism Network, and the mums within it, I would never have taken that step'. That is enough for me. That is what drives me to be the advocate that I am — the non-verbal child who comes in and who will wave and murmur a 'Hi' after coming for six months or the little girl who comes in and has not walked for 18 months and then last month came in walking on her toes, just through the perseverance of these parents bringing them. So I would say very positive.

It is great to be led by professionals too. Fiona Le Nepveu, who is our team leader, is magnificent. She is the president of MRAN. She is passionate, she is educated and she is knowledgeable. She is the one that answers those emails at 9 and 10 o'clock at night.

The CHAIR — Thank you so much, Shantelle. We really do appreciate it. If the secretariat agrees, we might get in touch with you post the hearing just with a few other questions about your service if that is okay.

Ms GRANT — Sure, more than happy to do that. Thanks for having us.

Committee adjourned.